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ABSTRACT

A parent-support group (Family Center at Nova University, Florida) for parents of handicapped infants and toddlers allowed parents to share their feelings and concerns. Parents were interviewed regarding three aspects: how they felt upon initial diagnosis, sources of support, and types of experiences that have promoted and inhibited coping. Parent feelings upon diagnosis included mourning, anger, fear, depression, self-pity, and guilt. The greatest source of support mentioned was other mothers. Grandparents and spouses were seldom named. The hardest parts of having a handicapped child were identified, including uncertainties about diagnosis, others' insensitivity, and difficulties in telling other people about the child's problems. Staff ratings of parent-child interaction suggested that mothers with the most positive ratings had generally supportive spouses and relatives, good peer support, responsive babies, relatively stress-free families, and a professional acting as a case manager. Negative feelings associated with professionals were cited as well as instances of supportive professional interaction. (CL)

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"An Interview Study with Mothers of Handicapped Children to Identify Both Positive and Negative Experiences That Influence Their Ability to Cope."

by

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Presented at the National Center for Clinical Infant Programs
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Within the last decade the focus for intervention of the handicapped child has shifted from the child to the family. Professionals have recognized that the quality of day to day exchanges between parent and infant has a profound effect on the infant's developmental outcome. From a transactional perspective, parent/infant interactions at any point in time reflect the outcome of earlier events. Factors that have a negative impact on the child's parents impede the developmental progress of the child.

Recognizing the importance of helping parents cope with the stress of parenting a handicapped child, the Family Center of Nova University instituted a parent support group as a component of the Ring-A-Round program. Ring-A-Round is a parent-child program for families with handicapped infants or toddlers. For the first hour of Ring-A-Round, parents attend classes with their child and share in developmentally appropriate activities. During the second hour, the children participate in a play group, while their parents meet with a parent coordinator over a cup of coffee. The agendas for the parent support component are planned by the group with suggestions from the parent coordinator. While specialists are brought in from time to time, the majority of the meetings are devoted to group discussion.

During the Ring-A-Round discussion sessions, parents spend much of the time sharing their feelings and concerns. Each set of parents has their own horror story about the turmoil they experienced when they first found out that their child

had a problem. For some parents this turmoil was short-lived. For others it was on-going. Recognizing that parents who can come to terms with their own negative feelings interact more effectively with their child, the Family Center staff initiated a parent interview study. The purpose of the study was to identify the kinds of experiences that influence the family's ability to cope with the stress of parenting a handicapped child. The study was conducted by members of the Ring-A-Round staff with 21 mothers enrolled in the Ring-A-Round program. The children ranged from three months to four years old, with Down's Syndrome as the most frequent diagnostic category.

Three lines of questions were pursued in the parent interview: How did you feel when you first found out that your baby had a problem and how have your feelings changed? Whom did you turn to for support? What kinds of experiences have you had that have made it easier or more difficult for you to cope with your situation? All interviews were conducted by members of the intervention team who were familiar with the infants and well-known to the families.

The first line of questioning focused on feelings. Initial reactions to finding out about their infants' problem were consistent with other studies. Parents characteristically went through a period of mourning as they gave up their fantasized child.

"Nothing could be wrong with my baby. My baby was going to be perfect."

"You kind of let your fantasies fade--that normal child growing up: ballerina, kindergarten, grade school, college..."

Almost all parents described feelings of anger, fear, depression, self-pity and guilt. Some parents had put the feelings behind them and described them in the past tense. For others the feelings were still with them.

"I felt angry like God was getting me back for something. I'm not real religious or anything, but I was raised Catholic. I don't know. I just thought that God was paying me back for something, but I couldn't think of anything that I had done that was so horrible."

"Fright--that's one feeling I had. I was real scared. 'Cause I didn't know exactly what Down's Syndrome was. All I could think of was retarded people that you see and feel sorry for in the store or the mall or something. Pity was another one. I thought I'd feel sorry for him. I thought there was no way I could raise him 'cause I'd feel sorry for him almost like I feel sorry for those people when I see them in the store."

"Always I feel like I could have done something different or better."

Parents who found out that their child was handicapped either at birth or shortly after were likely to describe their negative feelings as an episode that had passed.

"By the next day, I was still in shock but I was better, and then two or three days after that it was like I had accepted it."

"I cried every day of the first week--then every other day--then once a month. Now I cry about the same things as any other mother with a normal child would cry about."

In situations where the handicapped condition was not recognized at birth parents had more difficulty coming to grips with their child's handicap. Before the doctor acknowledged the problem, they struggled with terrible forebodings.

"Like I was yelling down a dark tunnel."

"Like no one was there."

"Something kept screaming in my head."

Then when the problem was acknowledged these same parents sought out other professionals who would give them a different answer. In most instances parents described the adjustment process as "painful and unsteady." Several mothers complained about being "out of synch" with their husbands. "I know my son is way behind other kids but my husband keeps saying,'Leave him alone, he's fine.'"

A second line of questioning pursued in the interviews concerned the support systems that parents used. Three out of twenty mothers described their husbands as their main support.

"He said,'What's wrong?' and I told him. He sat right down and said, 'Look, he's part of you and part of me. We're going to raise him. You know we'll see things through his eyes that no one else gets a chance to experience,' and stuff like that. I told him, 'I'll feel sorry for him.' He said, 'Well if you don't want him get your stuff, because I am going to raise him.'"

More frequently, mothers described their husbands as having too much difficulty with their own feelings to really serve as a support. "I was in bed with a C-section. My baby was behind glass. My husband was home crying. And other people's visitors

were walking down the corridor carrying flowers and presents."

Grandparents, like spouses, were seldom named by the mother as providing significant support. Over half of the mothers talked about how difficult it was to tell their parents or their in-laws that something was wrong with the baby. When they did finally tell them the grandmothers either reacted with sobbing and self-pity or they tried to assure the mother that the baby was all right. In most instances, mothers felt that their own mothers did not want to know about their baby's diagnosis and were not ready to share their concerns in an open and realistic way.

"She asks about him and stuff but never about the Down's Syndrome part. But then, we never talk that long to each other on the phone. Although we were very close when I lived at home--but things change."

The one source of support that was described by all parents in the study was other mothers of handicapped children. In particular, parents talked about the importance of organized parent support groups, where they meet with other mothers on a regular basis. Thirteen out of the twenty parents described the Ring-A-Round program at the Nova University Family Center as their most important resource.

The third line of questioning in the interview study related to painful and pleasurable experiences. In answer to the question, "What is the hardest part of having a handicapped child?" most parents talked about the insensitivity of other people. The doctors were too blunt or too evasive. Relatives were too intrusive or too detached. Spouses were too optimistic

or too pessimistic. Several parents described incidents where a parent or in-law had lashed out at them for having caused the problem.

Another answer to "What is the hardest part?" related to uncertainties around the diagnosis. Parents were distressed with professionals who told them "to wait and see" or who disagreed with their colleagues about a diagnosis. Several parents felt traumatized because they were told about a diagnosis either too early or too late. "If I had only known earlier I could have had a choice about giving it up." One parent who felt that the doctor had told her too soon before she had a chance to bond with her baby said, rather insightfully, "I guess there is no good time."

A third answer to "the hardest part" related to telling other people. Parents talked about how difficult it was to respond to strangers who asked if something was wrong. Even more difficult was telling close friends and relatives for the first time. "I hurt because of Mother. I knew it was harder for her to get the news than it was for me to tell it."

A final answer to "the hardest part" related to the responses of the child. Parents talked tearfully about babies who could not be comforted, babies who would not look in their eyes and babies who would not smile. Parents also discussed the pain of seeing a baby of the same age doing so much more than their baby.

Parents answers to "What are the things that make it better?" were very consistent. Every parent described a special pleasure. Several parents who had been told originally

that "their baby would outgrow it" described the doctor's admitting the problem as the beginning of things getting better. "At least I wasn't floundering. At least I was getting some help."

In order to explore the association between the responses to the interview and the general adjustment of the mothers, the staff members of the Ring-A-Round program were asked to rate the parents in terms of the quality of their interactions with their baby. The mothers who received the more positive ratings were likely to give the following kinds of responses.

Their spouse is generally supportive and they're both involved in the care of the baby.

Their baby smiles and is responsive.

One or more of their relatives accept the fact that there is a problem and pitches in to help.

They have good peer support.

They have either a pediatrician or other professional who acts as "case manager," gathering all the information and helping them with major decisions.

The diagnosis has been made and they know what has to be done.

Either they already have another healthy child or have been told that they could.

The family is relatively free of other major stresses.

In addition to the direct responses to the interview questions, parents volunteered information and suggestions that could be useful to professionals. Many of the negative feelings that parents described were associated with the doctors

who had been involved with their baby. The first time they were told about their child's problem was a critical event for many parents. They described the doctors as telling them too much or not enough, as talking to them as if they were doctors or as talking to them "as if we were idiots," as telling them too soon or too late, as blurting it out or beating around the bush.

A second complaint about doctors given by several interviewees was their failure to listen. Parents talked about telling the doctors over and over again that there was something wrong and always getting the answer that babies have their own time-table, babies grow out of it, or it is too early to tell. Obviously, these parents had no way of knowing how many times the doctors were right when they said that a baby would grow out of something.

A third complaint that parents kept making was that neither the hospitals nor the doctors were equipped with information on resources. Very few of the parents heard about support groups or intervention programs through their pediatricians.

Finally, several parents described pediatricians whom they felt were very supportive. Their most frequent comment was that the pediatrician really cared. "He made sure that my husband was with me and he sat us both down in his office."

"He touched me on the shoulder as if he knew I was hurting."

"He said that we might not hear all he was saying that day, but we could come back when we were ready."

The interview study reviewed in this article is based on a small and non-random sample. The interview was open ended and parents were encouraged to continue with a topic even when their answere were tangential: from this point of view it can be viewed as an exploratory study which supports an ecological model and which provides suggestions for further research and practices.

Recognize parents needs to have time to themselves, and time to enjoy their baby. Don't think that your specialty is the only thing that parent has to do.

Know the community resources.

Ident #_____ Sex_____

INTERVIEW FORMAT

Introduction: Thank for coming in -- sharing --

1. How did you get to Oral School (R-A-R)?
2. How old is _____? What is the diagnosis for_____?
3. When did you first suspect something was wrong?
4. Did you wait and see or move right away when you suspected?
5. Who told you? Who brought it to your attention?
6. When did it first come to the attention of professionals?
7. What did they say was wrong? Did all agree?
8. How did you feel during this time?
9. Was your husband with you when you were told? How did he react?
10. How much is he involved with taking care of _____?
11. Is there a difference with involvement with this _____ than with the others?
12. How did you tell the grandparents and close family members? What was their reaction? Do they live nearby? Have they been involved?
13. Once you knew something was wrong, how did you get information?
14. Who was most helpful and supportive during this time?
15. What was the worst part or the hardest time?
16. The most rewarding?
17. How do you feel when you are asked about _____?
18. When you talk about _____ what do you feel most comfortable saying?
19. Has that changed at all? Are you saying the same thing you said at first?
20. Has the diagnosis changed?
21. What progress have you seen?
22. How often do you and your husband go out? Who babysits?
23. If older children, how much do they help? How do you manage their activities? How do they react toward _____? What have you told them?
24. Do you think about having more children? What do the doctors say?
25. What more could have been done to help you?
26. Who or what has helped you the most?

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This study was supported by the A.L. Mailman Family Foundation. Interviews were conducted at Nova University Family Center by Barbara Lloyd, M.S. and Lorraine Greenhill, M.S. The interviewees were enrolled in the Ring-A-Round intervention program at the Family Center.